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Stillbirth Society of India

International Stillbirth Alliance Member

Inaugural Newsletter

STILLBIRTH
SOCIETY OF INDIA

www.stillbirth.org

From the Editor's Desk

Dr. Ayesha Ahmad
Founder Member and
Joint Secretary
Stillbirth Society of India

Global statistics estimate that every thirty seconds a stillbirth takes place in some part of the world, leaving behind pain and anguish. Avoidable stillbirths and perinatal deaths pose a great burden on the health of society and serve as a grim reminder to a preventable catastrophe.

It is my privilege to be editing the inaugural issue of SBSI e-newsletter. It introduces how the SBSI came into existence, its mission and objectives, the different committees and key members/ post-holders of the society.

SBSI aims to raise awareness of stillbirth [SB] and its causes, offer support to bereaved families by bringing them together, providing a platform for their voices and encouraging patient advocacy in families affected by SB and neonatal death.

There are two articles which discuss the most relevant and pressing needs in prevention of SB - the work-up in a pregnancy affected by SB and the importance of training care-givers in different aspects of perinatal pathology.

We believe that if our presence can bring a ray of hope to someone, can alleviate suffering for someone, our purpose of being care-givers is justified.

Message from the President

Stillbirth is one of the most devastating life events with substantial physical, psycho-social impact on women, families and society. It is a huge public health concern. In 2019, globally an estimated 1.9 million babies were stillborn and India topped the wrong charts with maximum number of still births.

Dr. Neelam Aggarwal

Founder President
Stillbirth Society of India

The irony is that stillbirths have been absent from most of the programs so far. They are invisible due to social taboos, stigma, isolation etc. There are no formal organizations in our country for raising voices of these bereaved parents & families.

It's my immense pleasure to introduce Stillbirth Society of India as the first formal organization dedicated to stillbirths in India. This is a long awaited and much needed step to draw attention on this important public health problem. Every unborn baby has the right to receive best care. All bereaved parents must have the highest quality respectful bereavement care.

'The temptation to quit will be greatest just before you are about to succeed.' - Bob Parsons

Message from the Vice-President

Dr. Nuzhat Aziz

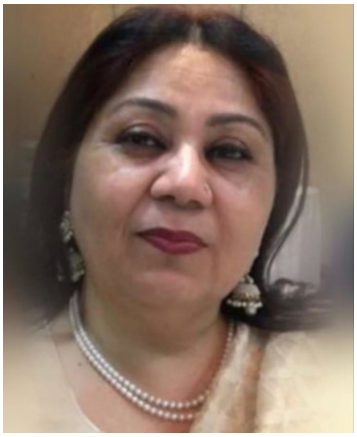
First Vice-President
Stillbirth Society of India

I chose obstetrics, then labour ward management as my focus of work, after post-graduation. Reducing stillbirth rates was a major focus for our team; we worked on streamlining Obstetric care, labour protocols (our book is available), perinatal mortality meets, CTG training and workshops, training in scalp electrode and fetal blood sampling. We had to streamline stillbirth evaluation, train staff in evaluation and bereavement counselling.

Perinatal mortality meets had to be a no-blame, learning experience and Prof. Hugh Philpott from South Africa helped us in 'partogram' as well as mortality meets as part of 'Every baby counts' programme.

The GAP protocol (growth assessment protocol) by the Perinatal Institute, UK was aimed at reducing stillbirth through improving SGA detection rates. We requested for help and created the customised Indian centile chart using our database and have been able to use the screening protocol to reduce stillbirths. Currently Fernandez Hospital has 10,000 births annually and our stillbirths rate is 5.4 per 1000 for 24 weeks and above and 3.0 per 1000 births for more than 28 weeks babies for our booked population. This is a journey of our team (60 doctors, midwives) and it was my honour to be one of the facilitators for this change.

Our Story



Dr. Tamkin Khan

Founder Secretary
Stillbirth Society of India

The idea of registering the SBSI was conceived by me about a year ago and registered on 11 Feb 2021. It is the first registered society in India and is affiliated with the International Stillbirth Alliance.

I can recount a few experiences which define for me the many facets of the problem of stillbirths in India.

As a senior resident walking into the labor room I heard a ward attendant telling a bereaved father waiting for his stillborn to be handed over to thefamily saying–look the labor room is very busy, should I worry about the live babies or should I waste time in handing over your dead baby?

I realised the complete lack of empathy and dignity in death.

The second incident I remember is when one of my patients was sent for a confirmatory sonography for an IUFD–the sonologist did not tell her about the fetal death but asked her to rush back to me as the baby is not well. She came rushing back in the hope that the baby was in danger and could be saved.

The complete lack of training in breaking bad news and dealing with grief in healthcare workers hit me then.

Lastly, I remember a lady with previous 2 stillbirths who came to us with her 3rd pregnancy which was again an IUFD. She delivered and after delivery, we encouraged her relatives to allow her to hold the baby—the usual practice in India is that the mother is not informed about the stillbirth nor encouraged to hold the baby. The reaction of the mother was priceless—ma'am even after delivering two babies I never felt like a mother. Though I will not be taking my baby home, but I felt like a mother today.

I realised the absolute lack of training of healthcare workers bereavement care.

The Lancet series of articles highlighting the enormity of the problem helped me focus on doing something concrete. Two other JNMC alumnae –Dr Asna Ashraf and Dr Ayesha Ahmad who shared my passion helped prepare the documents crystallising our vision, mission, and objectives statements. Dr. Shipra Kunwar, Dr Deepika Sinha, Dr Nafis Fatima, and Dr Bushra Fatima were also enthusiastic about this initiative and were among the 7 founding members of the society. Dr Asna Ashraf got the Society registered and affiliated to the International Stillbirth Alliance. Dr. Neelam Aggarwal from PGI, Chandigarh, already working with International Stillbirth Alliance on the Parents Voice Initiative, agreed to take over the leadership and guidance role as the first President of the society. Dr Nuzhat Aziz from Fernandez Hospital, working passionately for improving intrapartum quality of care for prevention of stillbirths, very kindly agreed to be our Vice President. The society shall ever be grateful to them for this. I would also like to thank our patrons Dr Pratima Mittal and Dr Evita Fernandez, international and national experts, committee chairs, and secretaries for agreeing to contribute with their expertise, experience, and passion in this humble but noble endeavour.

Membership of International Stillbirth Alliance

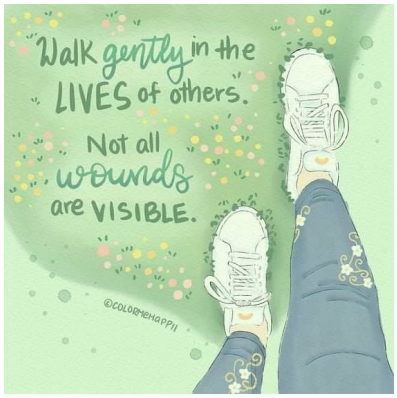
Dr. Asna Ashraf

Founder Member and Joint Secretary
Stillbirth Society of India

I had always been in awe of the work of organisations like SANDS, TOMMY's and Stillbirth Foundation Australia, often browsing through their beautiful websites and wondering and wishing when we in India will be able to do something like this to lessen the misery of parents affected by stillbirths and support them in their difficult times.

I was aware that the International Stillbirth Alliance (ISA) was a global organisation uniting bereaved parents and family members, health professionals and researchers to drive global change for the prevention of stillbirth and neonatal death and bereavement support for all those affected.

When we registered the Stillbirth Society of India in Feb 2021, I realised that developing a relationship with an organisation that could encourage and support us to reach our full potential, would be something that everyone could benefit from. With this premise in mind, I started exploring how we could become a member of the Alliance.



Who we are?

We are a non-profit organisation consisting of health-care professionals, researchers and individuals who have come together with the aim of reducing stillbirths and improving care for families who experience such tragedies.

Our Mission

- To reduce the incidence and impact of stillbirth by increasing awareness, research, education, and encourage advocacy and family support regarding stillbirth.
- To prevent as many stillbirths in India that occur after 28 weeks gestation, and to improve the quality of care received by families whose baby is stillborn through spreading awareness, education, advocacy and quality research and by timely identification and intervention in pregnancies at risk of stillbirth.

'Every Unborn baby should have an equal right to receive the best care while still unborn'...

Advisory Board Members

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Objectives

1	2	3	4	5
Measuring Every Stillbirth	Quality Care During Pregnancy & Childbirth	Increasing Awareness	Bereavement Care	Conducting Research & Generating Data for Policy Decisions

Support Group for Bereaved Families

Coping with the pain and heartache of losing a baby is always difficult. Grief is the reaction of overriding intense pain and emotion that follows; each person grieves in his own way and expresses it differently.

As part of SBSI, we want to help the families who have undergone a loss, to discover hope for the future and the strength to rebuild their lives and of their families.

We plan to achieve this by strengthening advocacy for stillbirth prevention and post stillbirth bereavement support.

Working Groups:

Research and Registry Group

Members:

- Dr. Achala Batra
- Dr. Amrita Chaurasia
- Dr. Aradhana Singh
- Dr. Asna Ashraf
- Dr. Ayesha Ahmad
- Dr. Bushra Fatima
- Dr. Harpreet Kaur
- Dr. Kiran Pandey
- Dr. Manju Puri
- Dr. Manisha Kumar
- Dr. Nuzhat Aziz
- Dr. Saroj Singh
- Dr. Seema Chopra
- Dr. Shrinivas Gadappa
- Dr. Smriti Agarwal
- Dr. Tamkin Khan

Convenor:

- Secretary SBSI

Consensus and Working Group on Guideline Formulation

Members:

- Dr. Amita Ray
- Dr. Anita Kaul
- Dr. K Aparna Sharma
- Dr. Bharti Sharma
- Dr. Manju Puri
- Dr. Neelam Aggarwal
- Dr. Nuzhat Aziz
- Dr. Pratima Mittal
- Dr. Shubha Phadke
- Dr. Tamkin Khan
- Dr. Uma Ram

Convenor:

- President SBSI
- Vice-President SBSI
- Secretary SBSI

Stillbirth Prevention Advocacy Group

Dr. Seema Tandon
Dr. Priti Kumar
Dr. Javvad Suri

Convenor: Secretary SBSI

Committees

Committee	Chairperson	Secretary
Committee for Study of Stillbirths From Maternal and Fetal Infections	Dr. Poonam Verma Shivkumar	Dr. Rehana Najam
Committee for Study of Stillbirths in Gestational Diabetes Mellitus	Dr. Bharti Maheshwari	Dr. Dalia Rafat
Committee for Study of Stillbirths From Hypertensive Disorders of Pregnancy and Renal Disorders	Dr. Anjoo Agarwal	Dr. Enas Mushtaq
Committee for Study of Stillbirths From Rh-Sensitisation	Dr. Mandakini Pradhan	Dr. Naini Tandon
Committee for Study of Recurrent Pregnancy Loss	Dr. Shipra Kunwar	Dr. Sujata Siwatch
Committee for Study of Genetic Causes of Stillbirths	Dr. Shubha Phadke	Dr. Shailja Singh
Committee for Study of Intrapartum Stillbirths	Dr. Aruna Nigam	Dr. Jogitha Unni
Committee for Study of Perinatal Pathology [Fetal and Placental] in Stillbirth	Dr. Sunil Jaiman	Dr. Nandita Kakkar
Committee for Study of Neonatal Death	Dr. Deepak Chawla	Dr. Aparna Chandrasekaran
Committee for Study of Stillbirths in ART	Dr. Sonia Malik	Dr. Sabahat Rasool

Committees

Committee	Chairperson	Secretary
Committee for Study of Stillbirths in Multiple Gestation	Dr. K Aparna Sharma	Dr. Reema Kumar Bhatt
Committee for Study of Stillbirths in Autoimmune Diseases	Dr. Shobha Gudi	Dr. Anita Rajorhia
Committee for Study of Stillbirths From Fetal Growth Restriction	Dr. Chanchal	Dr. Ayesha Ahmad
Committee for Study of Stillbirths in Intrahepatic Cholestasis of Pregnancy	Dr. Achla Batra	Dr. Amrita Chaurasia
Committee for Study of Stillbirths From Antepartum Haemorrhage	Dr. Sheela Mane	Dr. Shashi L Kabra Maheshwari
Committee for Study of Stillbirths in Maternal Obesity and Endocrine Disorders	Dr. Navneet Takkar	
Parent Voices Initiative Committee/ Bereavement Support	Dr. Neelam Aggarwal	Dr. Bharti Sharma
Committee for Public Awareness About Stillbirths	Dr. Sadhna Gupta	Dr. Shehla Jamal
Committee for Ethical and Medicolegal Issues in Stillbirth	Dr. Vidya Thobi	Dr. Subuhi Rizvi
Information Technology Committee	Dr. Asna Ashraf	Dr. Naima Afreen

Antepartum Stillbirth: Need For Indian Guidelines

Dr Anita Kaul MS, FRCOG, Dr Saba Aafrin MD

Dr. Anita Kaul
MS, FRCOG, FICOG,
Dip. in Fetal Medicine [FMF-UK],
Dip. Adv. Obst. Scanning [Lond.]
Clinical Director, Apollo Center for Fetal Medicine, Delhi

Introduction: Stillbirth [SB] is a devastating end to pregnancy for parents and caregivers. It is one of the most common adverse pregnancy outcome. An estimated incidence varies from 13.9 to 26.4 deaths per 1000 births in South Asia and Sub-Saharan Africa.

India has a stillbirth rate of 13.9 SB /1000 pregnancies.[1] 40% of stillbirths occur during labour, a loss that can be avoided with improved quality of care. The definition remains a matter of controversy, with recommendations varying between different obstetrical societies.

Globally, the lower threshold of gestational age for defining stillbirth ranges from ≥16 to ≥28 weeks of gestation, and the lower threshold for birth weight ranges from ≥400 to ≥1000 grams.[2] In our country, we should follow the WHO definition, with stillbirth defined as a baby that dies after 28 weeks but before birth. It is crucial to investigate properly because the cause of antepartum SB may be ascertained in around 60% of cases; important ones being placental insufficiency, fetal genetic and structural abnormalities, umbilical cord abnormalities, maternal infections, hypertensive disorders and diabetes.

A pragmatic approach is essential for a proper work-up in limited-resource settings. The present document aims to review the existing protocols for the evaluation of SB and summarise relevant investigations. [3,4,5]

Maternal History: Evaluation starts with detailed history, which may help to isolate an etiology. This must include questions about family history, which can identify an inherited cause for Stillbirth; maternal history, including obstetrical and medical history; and the history of the current pregnancy.

Examination: It is essential to look for specific fetal pathologic conditions and, at the time of delivery, to carefully examine the fetus, the placenta, and the umbilical cord.

Investigations: The relevant investigations are summarised below, which should be modified according to clinical evaluation.

Maternal

- Complete blood count. It is recommended that platelet count be repeated twice weekly to test for occult disseminated intravascular coagulopathy.
- Blood group and Rh factor
- Indirect Coomb's test should be done in Rh-negative pregnancies.
- Maternal blood sugar (random) should be tested in all women to diagnose maternal DM. The test should be done as soon as possible after the diagnosis of SB as euglycemia returns within a few hours of SB.
- Bile acids and liver enzymes should be seen if cholestasis of pregnancy is suspected.
- Coagulation profile and plasma fibrinogen levels are recommended in all cases to exclude massive placental abruption as a cause of SB and for evidence of developing maternal coagulopathy.
- C reactive protein is suggested in maternal sepsis or haemorrhage to assess multi-organ failure.

- Fetomaternal haemorrhage as a cause of SB should be assessed in all cases. It can be tested by performing the Kleihauer Betke test or Flow Cytometry. The latter is generally not available, and the former can be easily included in a lab protocol as it is a cheap test. As the fetal red cells might quickly clear from maternal circulation, it should be done as soon as possible after the diagnosis of fetal death, or latest, within 3 hours of SB.

- Tests for maternal bacteriology [Blood culture, Mid stream urine culture, Vaginal swab, Cervical swab] should be done if there is suspicion of maternal sepsis/chorioamnionitis. [fever, flu-like symptoms, purulent liquor, prolonged rupture of membranes]

- Tests for maternal serology are indicated when there is suspicion of infection. The common organisms implicated in SB are Cytomegalovirus, Herpesvirus, Toxoplasma gondii, Parvovirus B19, Listeria monocytogenes and Treponema palladium. At the very least, a TORCH IgG/IgM and a VDRL should be checked. Parvovirus can be sent if there is a clinical history of fever, rash or a family member showing the same symptoms.

- Thrombophilia testing: Testing for lupus anticoagulant, anticardiolipin IgG, IgM, anti-b2-glycoprotein IgG, IgM is recommended in all women antiphospholipid antibody syndrome has been found to be associated with SB. Since inherited thrombophilias have not been associated with SB, the woman need not be tested for these.

- Maternal thyroid function [TSH, FT4, FT3] is recommended in all cases to screen for occult maternal disease

- Anti-Ro/LA (SSA-SSB) should be done if there is evidence of hydrops, endomyocardial fibroelastosis, or atrioventricular node calcification at postmortem

- Haemoglobin electrophoresis is recommended in cases where alpha thalassemia is considered as a cause of SB [hydropic fetus, anaemic mother]
- A toxicology screen is indicated if substance abuse is suspected, although this is less seen in the Indian population
- Evaluation for parental mosaicism or balanced translocation indicated in cases of recurrent miscarriage, previous history of unexplained SB, suspected fetal aneuploidies, unbalanced fetal translocation or if fetal genetic testing fails to reveal a cause.

Fetal

- Post mortem examination is recommended in all cases of SB. A specialist perinatal pathologist can provide additional information in around 30% of cases. However, there are very few perinatal pathologists in our country.It is crucial to get proper consent before the autopsy to determine if the parents want a complete autopsy, limited autopsy, or external examination.

- A complete examination includes external Examination, infantogram, autopsy, and histopathological examination of the internal organs and the placenta and cord.
- A limited autopsy is just examining the part which was involved in the disease process as identified by ultrasound
- External Examination involves no opening up of the dead fetus but merely phenotypic Examination.
- The range of Examination might be restricted by parental consent, thus limiting the information.
- Karyotype +/- or better still, a chromosomal microarray is recommended to look for aneuploidy, single-gene disorders and sexing of the baby.
- Fetal and placental microbiology may provide additional information about associated subclinical infections.

Key Message:

The best strategy for evaluating antepartum stillbirths is unclear due to the lack of good quality evidence to guide recommendations. Despite a comprehensive investigation, many parents will be left without a definite answer for a stillborn baby. A systematic approach is essential while evaluating the potential causes of SB.

The need of the hour is to adapt the existing evidence and formulate guidelines keeping in mind the available resources, with an obstetrician who is aware of the clinical history playing a pivotal role in judiciously chosen investigations.

As part of the endeavours of the Stillbirth Society of India, we plan to bring expertise under a single umbrella, generate evidence and provide guidance on the best approach for investigating SB suited for low resource settings.

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Perinatal Pathology in Stillbirth: Untapped Potential of Investigation

Dr Sunil Jaiman MD, DipRCPath, FCAP

Dr. Sunil Jaiman

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Stillbirth is an agonizing event for parents and frustrating for health care providers, often because of its unpredictability. It remains a difficult area pathologically in terms of practice as well as diagnostically. Stillbirth autopsies are emotionally difficult and practically challenging for most pathologists. For these reasons and because of inadequate training, stillbirths have received relatively little attention from pathologists across the world and more so from resource-poor countries.

The factors underlying fetal death can be identified and understood in large part and indeed, detailed fetal autopsies, including thorough placental evaluation are considered the most useful tool in the evaluation of stillbirths. It is in these settings that the importance of perinatal pathology lies: the need for accurate diagnosis of the cause of death. This ascertainment of a diagnosis helps in:

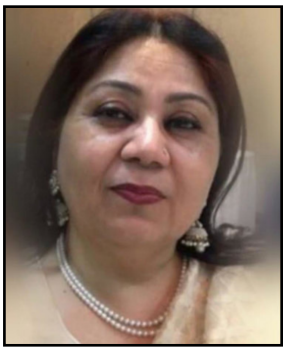
- Providing genetic counselling
- Bereavement closure
- Implication of possible recurrence in future pregnancies
- Intelligent family planning

My experience and expertise with Perinatal Pathology spans sixteen years. I was initiated into placental and fetal autopsy pathology in 2004 by Dr Swarnalata G, Head Anatomic Pathology Apollo Hospitals, Hyderabad, India. Although the involvement was serendipitous and ponderous, the entanglement with the mystic organ placenta and its fetus has been voluntary and the submission complete.

In 2010, the unconditional support and mentoring by Dr Evita Fernandez, Chairperson of Fernandez Foundation enabled me to advance Perinatal Pathology as a specialty in Hyderabad, India. It was here that I imbibed empathy for grieving mothers. It was here that during counselling I realized how traumatic it is for a mother to lose her baby. First, she holds herself guilty; secondly, she is forced to feel guilty by some insensitive in-laws and she must be exceptionally lucky not receive their wrath or condemnation; thirdly I came across at least half a dozen cases where a mother would beg me tears streaming to convince her husband that it was not her fault, that he should not desert her. There is nothing more gutting than to hear these horror stories.

I dedicate my work to all the families who have encountered fetal or neonatal loss. Though nothing can compensate for the bereavement, I hope that by a meticulous study of the fetal and neonatal tissues I would be able to provide some comfort and help the healing process.

Founder Members



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